16 Harrow JR. Bandwidth: the silicon of the 21st century! www.digital.com/rcfoc/980309.htm#ItsAll_About (accessed 9 March 1998).
17 Jadad AR, Gagliardi A. Rating health information on the internet: navigating to knowledge or to Babel? *JAMA* 1998;279:611-4.
18 Kim P, Eng TR, Deering MJ, Maxfield A. Published criteria for evaluating health related web sites: review. *BMJ* 1999;318:647-9.
19 Norman GR, Shannon SI. Effectiveness of instruction in critical appraisal (evidence-based medicine) skills: a critical appraisal. *Can Med Assoc J* 1998;158:177-81.
20 Haynes RB, Jadad AR, Hunt DL. What's up in medical informatics? *Can Med Assoc J* 1997;157:1718-9.
21 Jadad AR, Enkin M. The new alchemy: transmuting information to knowledge in an electronic age. *Can Med Assoc J* (in press).
22 Ad Hoc Committee on Health Literacy for the Council of Scientific Affairs, American Medical Association. Health literacy: report of the Council of Scientific Affairs. *JAMA* 1999;281:552-7.
23 Nisbett RE, Ross L. *Human inference: strategies and shortcomings of social judgement.* Englewood Cliffs, NJ: Prentice-Hall, 1980.
24 McNamee D. Public's perception of RCTs. *Lancet* 1998;351:772.
25 Jadad AR. *Randomised controlled trials: a user's guide.* London: BMJ Books,1998.
26 Haynes RB, Sackett DL, Gray JAM, Cook DJ, Guyatt GH. Transferring evidence from research to practice. I. The role of clinical care research evidence in clinical decisions. *ACP Journal Club* 1996;1:196-8.
27 Spielberg AR. On call and online: sociohistorical, legal, and ethical implications of e-mail for the patient-physician relationship. *JAMA* 1998;280:1353-9.
28 Smith J. "Internet patients" turn to support groups to guide medical decisions. *J Natl Cancer Inst* 1998;90:1695-7.
29 Melinda's home page. www.monkey-boy.com/melinda (accessed 15 May 1999).
30 Canadian Cancer Research Group. www.ccrg.com (accessed 15 May 1999).
31 MediXperts. www.mediconsult.com/home/service/ (accessed 15 May 1999).
32 America Online. Web center: health. www.aol.com/webcenters/health/home.adp (accessed 15 May 1999).
33 Coiera E. The internet's challenge to health care provision. *BMJ* 1996;312:3-4.
34 The end of privacy. *Economist* 1999 May 1:15-6.
35 Bennahum DS. Daemon seed: old email never dies. *Wired* 1999;7:100-11.
36 Frisse ME. What is the internet learning about you while you are learning about the internet? *Acad Med* 1996;71:1064-7.
37 Goodman KW. The issues and forces that shape informatics. *MD Computing* 1999;16:24-6.
38 Garriot GL. Low earth orbiting satellites and internet-based messaging services. www.isoc.org/isoc/whatis/conferences/inet/96/proceedings/g1/g1_1.htm (accessed 14 May 1999).
39 National Science Foundation. Science and Engineering Indicators 1998. IT and the citizen: equity issues. www.nsf.gov/sbe/srs/seind98/frames.htm (accessed 15 May 1999).
40 United Nations Development Programme. Human development report. www.undp.org/hdrol(accessed 3 September 1999).
41 Platt C. Ethernet at 60,000 feet: telecom's new jet age takes off. *Wired* 1999;7:150-5.
42 Kurzweil R. *The age of spiritual machines: when computers exceed human intelligence.* New York: Viking, 1999.

Helping patients access high quality health information

Sasha Shepperd, Deborah Charnock, Bob Gann

Department of Primary Health Care and General Practice, Division of Primary Care and Population Health Sciences, Imperial College of Science Technology and Medicine, London W2 1PG
Sasha Shepperd
lecturer

Division of Public Health and Primary Health Care, University of Oxford, Institute of Health Sciences, Oxford OX3 7LF
Deborah Charnock
research officer

Centre for Health Information Quality, Winchester SO22 5DH
Bob Gann
director

Correspondence to: Sasha Shepperd S.Shepperd@ic.ac.uk

The provision of consumer health information was pioneered in the United States: organisations such as Planetree (a not for profit, community based healthcare initiative) were among the first to provide information services.[1] Over the years several organisations in the United Kingdom—including the College of Health, the Help for Health Trust, the Health Education Authority, the Health Education Board for Scotland, and self help groups—have provided information on a wide range of health topics directly to patients or consumers. Similar initiatives have been undertaken in Europe, Canada, Australia, and New Zealand.[2] More recently, developments in Britain such as local consumer health information services, the Patient Partnership Strategy,[3] and initiatives at the King's Fund[4 5] have improved awareness of and access to evidence based consumer health information. These developments have come at a time when the amount of health information is increasing, particularly through the internet—and amid increasing concern about the varying quality of health information accessed by patients. We outline some steps to help health professionals advise patients on where to find good quality health information in this rapidly changing field.

Sources of consumer health information

Some of the organisations in the United Kingdom that are funded to provide health information for patients and the public are listed in box 1.

The internet
The internet offers access to health information provided by many different organisations and agencies. Several providers offer gateway services that operate a selective process, only including information that meets certain criteria. First time users may find that gateway sites are a helpful initiation to this type of information. Box 2 gives examples of widely used gateway sites that use explicit guidelines for selecting information. A fuller listing can be found in a review by Kim et al.[7] Box 3 gives examples of other well known websites that provide public access to health information. As these sites contain links to other organisations and services, including the sites of national self help groups, we have not listed addresses for individual services. These examples are limited by the dynamic nature of the web. Also, even where information is selected to conform with explicit criteria, the basis for these criteria is not always clear.

Appraisal tools for consumer health information

Assessment tools are available to judge the content of consumer health information, and many organisations have developed internal systems of appraisal. Several problems must be resolved before appraisal becomes common practice, including the resources required to

Summary points

Patients require access to good quality, evidence based information so they can take an active part in decisions about their health care

The amount of information available to patients is increasing, particularly through the internet

The quality of this information remains variable

Health professionals need to be able to direct patients to sources of good quality consumer health information, including health related websites

Box 1: Sources of consumer health information

• National Freephone Health Information Service (tel: 0800 66 55 44)—all health authorities are required to provide a freephone health information service for their residents. There are various local arrangements for the provision of these lines, but all services work to the same standards and provide access to information for patients and the public on the same number.

• NHS Direct (tel: 0845 4647)—24 hour, nurse led telephone advice line, currently covering 40% of England. The whole country will be covered by the year 2000.[6]

• Help for Health Trust (tel: 01962 849 100; **www.hfht.demon.co.uk/**)—based in Winchester, the trust provides information as part of the Health Information Service and NHS Direct Hampshire; it maintains a large consumer health information library and databases, including Helpbox, which provides details of national self help groups and references to self help literature on a wide range of health issues. Helpbox is now available as a Windows compatible package, and future editions will include details of the quality of each publication.

• Centre for Health Information Quality (tel: 01962 863511; enquiries@centreforhiq.demon.co.uk; **www.centreforhiq.demon.co.uk/**)—funded by the NHS Executive as a central resource to facilitate the production and dissemination of high quality patient information for health service users.[3] Focuses on information describing treatment choices and outcomes; does not currently provide access to information on specific conditions or treatments, but provides advice on quality guidelines and initiatives and works directly with NHS and patient representatives to raise awareness of key issues in the development of consumer health information.

• National Electronic Library for Health (www.nelh.nhs.uk/)—a key component will be a virtual "floor" (NHS Direct On-Line) for patients and the public; this will provide easy access to best current knowledge. NHS Direct On-Line will help people to address three questions:

How can I stay healthy and reduce my risk of disease?
Should I see my doctor?
Am I getting the right type of care and treatment for my health problem?

assess the vast amount of health information written for consumers.

Quality

Judging the quality of consumer information is not always straightforward. Guidelines and checklists have been published for appraising the quality of written consumer health information.[8–10] Commonly agreed criteria include currency and sources of information, reliability, relevance, and accuracy. For most of these instruments, however, details of reliability or validity are inadequate, and some seem to have been derived from a variety of unstated perspectives.[11] Instructions on use and interpretation are not always explicitly stated.

Retrieving high quality online information that may be of use can also be a problem. Difficulties in searching and using information in this rapidly changing environment have been well described.[7 12] The advent of the internet has led to a proliferation of appraisal tools and quality checklists, particularly in relation to the development of gateway sites.[7] The reliability and validity of these checklists are not always clear. Box 4 shows two validated tools developed for rating the quality of consumer health information.

Readability

Readability tests are designed to provide a quantifiable assessment of how easy text is to read. A criticism of readability tests is that they do not take into account a patient's prior experience and motivation. During the course of an illness patients may rapidly become familiar with quite complex terminology.[16] Gender, culture, and age should also be considered when these measures are used.[17] Tests of readability are generally based on the number and length of sentences and the number of long words (usually defined as words with three or more syllables). Commonly used measures of readability include Flesch (which may be found on many word processing packages)[18] and Gobbledygook.[19] In addition to quality and readability, the evidence base of the information and the involvement of consumers in the production of the material base should be considered.

If no information is available

If good quality health information is not available an alternative is to produce a leaflet or website. Outlining the steps to good practice for those setting out to write

Box 2: Gateway sites

Healthfinder (**www.healthfinder.gov/**)—a US government site that provides access to health information from a range of sources, including government agencies, voluntary groups, and professional organisations. It has links to Medline Plus and other online databases

Health On the Net Foundation (**www.hon.ch/**)—an international, not for profit initiative based in Geneva. It provides a database of evaluated health materials and also promotes the use of the HON code as a self governance initiative to help unify the quality of medical and health information available. Users of website health information displaying the HON logo can be assured that the material has been developed in accordance with these guidelines

Organising Medical Networked Information (**www.omni.ac.uk**)—based at the University of Nottingham, OMNI provides access to good quality biomedical and health information from the internet worldwide. It has been developed primarily for medical professionals, but consumers may find it useful

Box 3: Online sources of consumer health information

HebsWeb (**www.hebs.scot.nhs.uk/**)—the website for the Health Education Board of Scotland; a popular site providing access to a wide range of consumer health information and resources through a virtual health centre

HPIC Health Promotion Information Centre (**www.hea.org.uk.hpic/**)—the national centre for health promotion information and advice in England and part of the Health Education Authority; includes access to databases covering a variety of health issues and topics in a range of formats

Medline Plus (**www.nlm.nih.gov/medlineplus/**)—supported by the US National Library of Medicine; provides access to a wide range of databases, including the abstracts of articles indexed on Medline.

National Institutes of Health (**www.nih.gov/health/consumer/**)—provides access to databases of consumer health information published by the US National Institutes of Health. The NIH search engine is also available

Patient UK (**www.patient.co.uk/**)—designed to direct non-medical people in the United Kingdom to information about health related issues; maintained by two general practitioners responsible for the patient information leaflet service (PILS)

1 Planetree. www.planetree.org; accessed 2 August 1999.
2 Rees A, ed. Medical consumerism: library roles and initiatives. In: *Managing consumer health information.* Phoenix: Oryx Press, 1991.
3 NHS Executive. *Patient partnership: building a collaborative strategy.* Leeds: NHS Executive, 1996.
4 Dunning M, Abi-Aad G, Gilbert D, Hutton H, Brown C. *Turning evidence into everyday practice.* London: King's Fund, 1999.
5 Coulter A, Entwistle VA, Gilbert D. *Informing patients: an assessment of the quality of patient information materials.* London: King's Fund, 1998.
6 NHS Executive. *Information for health: an information strategy for the modern NHS 1998-2005.* Leeds: NHS Executive, 1998.
7 Kim P, Eng TR, Deering MJ, Maxfield A. Published criteria for evaluating health related web sites: review. *BMJ* 1999;318:647-9.
8 Coulter A. Give patients solid information. *Management in General Practice* 1996;20:40-2.
9 Entwistle VA, Sowden AJ, Watt IS. Evaluating interventions to promote patient involvement in decision-making: by what criteria should effectiveness be judged? *J Health Serv Res Policy* 1998;3:100-7.
10 Coulter A. Evidence based patient information. *BMJ* 1998;317:225-6.
11 Entwistle VA, Sheldon TA, Sowden AJ, Watt IS. Supporting consumer involvement in decision making: what constitutes quality in consumer health information? *Int J Health Care* 1996;8:425-37.
12 Jadad AA, Gagliardi A. Rating health information on the internet. *JAMA* 1998;279:611-4.
13 Charnock D. *The DISCERN handbook: quality criteria for consumer health information.* Abingdon: Radcliffe Medical Press, 1998.
14 Charnock D, Shepperd S, Gann B, Needham G. DISCERN—an instrument for judging the quality of consumer health information on treatment choices. *J Epidemiol Community Health* 1999;53:105-111.
15 Mitretek Systems Innovative Technology in the Public Interest. hitiweb.mitretek.org/hswg; accessed 2 August 1999.
16 Meade C, Smith CF. Readability formulas: cautions and criteria. *Patient Educ Couns* 1991;17:153-8.
17 Secker J, Pollard R. *Writing leaflets for patients: guidelines for producing written information.* Edinburgh, Health Education Board for Scotland, 1995.
18 Flesch R. A new readability yardstick. *J Appl Psychol* 1948;32:221-33.
19 Ewles L, Simnett I. *Promoting health: a practical guide.* London: Scutari Press, 1995.
20 Smith T. Information for patients. *BMJ* 1992;305:1242.
21 Sless D, Wiseman R. *Writing about medicines for people.* Canberra: Australian Government Publishing Service, 1997.
22 Wright P. Writing and information design of healthcare materials. In: Candlin C, Hyland K, eds. *Writing: texts, processes and practices.* London: Addison Wesley Longman, 1998.

> **Box 4: Examples of tools for assessing the quality of consumer health information**
>
> DISCERN (**www.discern.org.uk**)—developed to assess the quality of health information on treatment choices.[13][14] A number of hints are given after each question to guide the user. Areas covered are: bias in the material, a clear statement of aims, references and additional sources of support and information, uncertainty, risks and benefits (including those of opting for no treatment), and treatment options. DISCERN also alerts the user to concepts such as shared decision making, and quality of life. An online version (www.discern.org.uk) is currently being tested.
>
> The Health Information Quality Assessment Tool (**hitiweb.mitretek.org/iq**)—the Health Summit Working Group in North America (hitiweb.mitretek.org/hswg) is currently developing a reliable and valid appraisal tool for users of health information on the internet.[15] The tool is interactive and is potentially useful for patients wishing to evaluate the overall quality of health related websites. The main areas currently covered are credibility, content, disclosure, links, design, interactivity, and caveats (information on the function of the site).

leaflets for patients, Smith emphasised the time it takes to produce clear, unambiguous material that patients will use.[20] In addition to following validated quality criteria, writers should take patients' information needs into account and be aware of how people will read what they have written.[21][22] This will require involving patients in developing and testing materials.[10] Before embarking on this lengthy process, however, a first step is to check if high quality information already exists.

Framework for teaching and learning informed shared decision making

Angela Towle, William Godolphin

Faculty of Medicine, University of British Columbia, Vancouver, BC, Canada V5Z 4E3

Angela Towle
director, MD undergraduate programme

Department of Pathology and Laboratory Medicine, University of British Columbia

William Godolphin
professor

Correspondence to:
A Towle
atowle@interchange.ubc.ca

Patients should be involved in making decisions about their health care. The ethical imperative of autonomy is reflected in legal trends that require a high standard of disclosure for informed consent, amounting to a principle of informed choice.[1-3] Outcomes of care and adherence to treatment regimens improve when patients are more involved.[4][5] Consumerism is part of the social spirit, and governments exhort citizens to take more responsibility.

Models of doctor-patient encounters that result in increased involvement of patients and that are informed by good evidence have been termed, for example, "informed patient choice"[6-8] but do not describe the interactive process clearly. We use the term informed shared decision making to describe decisions that are shared by doctor and patient and informed by best evidence, not only about risks and benefits but also patient specific characteristics and values. It occurs in a partnership that rests on explicitly acknowledged rights and duties and an expectation of benefit to both.

We propose that a demonstrated capacity to engage in informed shared decision making is charac-

> ## Summary points
>
> Competencies for the practice of informed shared decision making by physicians and patients are proposed
>
> The competencies are a framework for teaching, learning, practice, and research
>
> Challenges to putting informed shared decision making into practice are perceived lack of time, physicians' predisposition and skill, and patients' inexperience with making decisions about treatment

terised by a set of necessary and sufficient competencies. By competencies we mean the knowledge, skills, and abilities that represent the instructional intents of a programme, stated as specific goals.[9] They are a framework for teaching, learning, practice, and investigation